

## UNDERSTANDING PATIENT PERSPECTIVES

**The lived experience of Dupuytren's disease of the hand**

Anna L Pratt and Geraldine Byrne

**Aims.** To describe patients' experiences of living with Dupuytren's disease.

**Background.** Dupuytren's disease is a chronic, progressive deformity of the hand which limits active extension of the fingers due to advancing and irreversible flexion deformity. It is estimated that two million people are affected by the condition in the UK. Nurses may frequently encounter patients with this condition in a wide range of settings. However, the disease is neglected in the nursing literature and little is known about patients' experience of living with the condition.

**Design.** A phenomenological approach, using Colaizzi's method, was employed.

**Method.** Semi-structured interviews were conducted with six men and one woman diagnosed with Dupuytren's disease.

**Results.** Four interlinking themes emerged. Theme 1: Awareness of Dupuytren's disease describes participants' experiences of recognising and acknowledging the disease, which often did not occur until functional ability was restricted. Theme 2: Living with Dupuytren's disease describes how patients coped with the disease and adapted their activities to maintain independence. Theme 3: Deciding on treatment illuminates how patients decided on treatment and highlights a lack of information and support from health professionals. Theme 4: Receiving treatment articulates participants' experience of surgical treatment and post surgical rehabilitation.

**Conclusions.** The findings revealed that people living with Dupuytren's disease receive little information about their condition and possible treatment from health professionals yet high quality and accurate information is required for patients to understand their condition and the treatment options available.

**Relevance to clinical practice.** People with Dupuytren's disease do not always recognise their condition until it has significantly progressed. Following diagnosis they need accurate and up-to-date information about their condition and treatment options. Nurses have an important role to play in raising awareness of the disease, educating patients about its features and progression and enabling them to become active partners in decisions about treatment.

**Key words:** Dupuytren's disease, interviews, nursing, patient experiences, patient information, phenomenology

Accepted for publication: 19 May 2008

**Introduction**

Dupuytren's disease is a chronic, progressive deformity of the hand which limits active extension of the fingers due to advancing and irreversible flexion deformity (McFarlane 1997). It typically affects men of northern European decent

and in the UK two million people are estimated to have the condition which can also affect the foot and is associated with Peyronies disease (Townley *et al.* 2006). The disease usually presents at the mean age of 55 years for men and 65 for women, with men displaying a more severe disease profile (Godmundsson *et al.* 2000). A hereditary link is recognised

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(McFarlane 1997, Townley *et al.* 2006) and some authors suggest it is associated with diabetes, increased smoking and alcohol consumption (Godtfredsen *et al.* 2004). Dupuytren's disease predominately affects the ring and little fingers with these fingers forced into a progressive flexion deformity, limiting the ability to extend the fingers (Azad *et al.* 2001) in preparation for grip (Aulicino 1995, Boscheinen-Morrin & Conolly 2000). The disease usually presents with a tender nodule or progressive band development in the palm with pitting occurring as a result of fibres contracting in the band (McGrouther 1985). Hands are the primary way of interacting with the environment and hand deformities causing a restriction in range of motion may have a significant impact on an individual's ability to engage in and complete everyday activities.

Nurses working in a wide range of hospital and community settings are likely to frequently encounter people with Dupuytren's disease. However, little has been written in the nursing literature about the disease, its onset and the treatment options available. Patients' experiences of living with the disease have also been neglected. This study aimed to explore patients' experience of living with Dupuytren's disease and, using Coliazzi's method, to articulate a fundamental structure of the phenomena.

## Background

Living with a long-term, progressive and degenerative condition is likely to have a significant impact on an individual's life (DH 2005a). The different perspectives on disease and illness between patients and professionals have been highlighted and the need to understand illness and the experience of illness from the patients' perspective has been emphasised (Thorne & Paterson 2000). In the UK and elsewhere, healthcare policy has articulated a vision of patient-centred care (Department of Health 2002, 2004). An understanding of patients' experiences of illness and healthcare is central to such a vision (DH 2005b) yet the experience of people living with Dupuytren's disease remains neglected.

Literature related to Dupuytren's disease is mainly quantitative research assessing surgical interventions, describing postoperative care and clinical reports of the disease (Andrew *et al.* 1991, McFarlane 1997, Glassey 2001, Bulstrode *et al.* 2004). The most common evidence-based treatment is surgery to correct the deformity, with postoperative rehabilitation to restore hand function (Wilson 1997, Bulstrode *et al.* 2004). There is no cure for Dupuytren's disease and further progression may require repeated surgical intervention (Adam & Loynes 1992, McFarlane 1995). Surgery can involve a variety of corrective procedures without loss of digit

flexion, the main ones being fasciotomy (division of the band) or a fasciectomy (resection of the aponeurosis) (Draviaraj & Chakrabarti 2004). Following surgery, patients attend for postoperative skin care at a nurse-led dressing clinic and rehabilitation, usually by a hand therapist, to improve range of motion (Boscheinen-Morrin & Conolly 2000).

A second treatment option is percutaneous fasciotomy which uses a needle to divide the Dupuytren band at the metacarpophalangeal joint and is less intrusive than traditional surgery. It has recently become available in the UK following increased popularity in France, but there is little long-term evidence of benefit (Foucher *et al.* 1998, 2001). Another reported treatment is splinting the fingers to minimise deformity progression and maximise range of motion (Ball & Nanchahal 2002). However, there is little research to confirm efficacy. Both percutaneous fasciotomy and splinting are suggested as an appropriate treatment choice for those not suitable for general anaesthetic and surgery (Foucher *et al.* 1998).

Despite an extensive literature review, no research describes the experience of patients living with Dupuytren's disease. Some literature describes living with other conditions that restrict hand movement, such as rheumatoid arthritis, or following hand injury. One of the major issues identified was the impact of restricted movement on the ability to undertake daily activities. Gustafsson *et al.* (2000, 2002) describe problems experienced by those who had acute traumatic hand injury in eating, dressing and attending to personal hygiene. Experiencing practical problems in everyday life was described as stressful and led to frustration, anger and feelings of vulnerability. Similar findings were reported in studies of people with hand deformity due to rheumatoid arthritis (Ryan 1996) and those with congenital hand conditions and hand deformities (Rumsey *et al.* 2003). People with hand deformities frequently described developing adaptive strategies to deal with their limitations (Gustafsson *et al.* 2000) such as devising gadgets or devices to make everyday life easier (Yoshida & Stephens 2004), or relying on others for assistance (Chan & Spencer 2004). However, a balance had to be found between the need for assistance and maintaining independence (Helm & Dickerson 1995, Gustafsson *et al.* 2000).

Hands are usually visible in social encounters and often used extensively during communication (Grunert *et al.* 1988, Rumsey *et al.* 2003). People with rheumatoid arthritis highlighted concerns that their visible hand deformities affected their dexterity and made them self-conscious (Iaquinta & Larrabee 2004). Rumsey *et al.* (2003) found those with disfiguring hand conditions felt their hand appearance had a significant impact on their lifestyle due to

embarrassment and self-consciousness, while Grunert *et al.* (1988) reported that, following hand injury, personal relationships altered and sexual contact was reduced.

The literature indicates living with a hand deformity may have a significant impact on an individual's life and lifestyle, although research specifically investigating Dupuytren's disease is lacking. At the Regional Plastic Surgery Unit, where this study was undertaken, patients frequently raised issues about the disease process and functional impairment prior to corrective surgery. The aim of this study was to explore and describe what it is like to live with Dupuytren's disease, thereby raising awareness and increasing knowledge of the condition.

## Methods

### Ethical consideration

Ethics and research approvals were obtained from the Local Research Ethics Committee and Research Monitoring and Governance Committee. Confidentiality was the main ethical issue and all names have been changed to maintain anonymity.

### Design

A hermeneutic existential phenomenological approach was used to guide the study. This approach is based on Heidegger's existential perspective, which acknowledges that an understanding of a person cannot occur in isolation from the person's world (Heidegger 1962). It emphasises that it is only possible to interpret something in relation to our own lived experience, as we make sense of it through our existence (Walters 1995). Semi-structured interviews were chosen as the most suitable method to gather rich in-depth data to understand individual's lived experience of Dupuytren's disease. This approach does not attempt to seek absolute truth but relies upon a systematic process to ensure rigour, whilst acknowledging the final interpretation as tentative (Creswell 1998, Rapport 2005).

### Participants

A purposive sample of people living with Dupuytren's disease was used and therefore a confirmed diagnosis was required. Sixteen patients who met the inclusion criteria (see Table 1) were sent a letter of invitation together with an information sheet, reply slip and a self-addressed envelope to indicate their participation.

Due to the incurable nature of the disease, pre and postoperative participants were included to gain insight into

**Table 1** Study inclusion and exclusion criteria

Inclusion criteria	<ul style="list-style-type: none"> <li>• Confirmed diagnosis of Dupuytren's disease of the hand</li> <li>• Under the care of the one named Consultant Plastic Surgeon</li> <li>• Either completed their rehabilitation phase following an operation no more than 12 months ago or currently on the waiting list for an operation.</li> <li>• Patients not treated by lead researcher*</li> </ul>
Exclusion criteria	<ul style="list-style-type: none"> <li>• Under 18 years of age</li> <li>• Unable to give informed voluntary written consent</li> <li>• Unable to have a good understanding of and ability to, communicate in the English language</li> <li>• Dupuytren's patients under the care of the one named consultant currently receiving rehabilitation following their operation</li> <li>• Patients previously treated by lead researcher*</li> </ul>

\*At the time of the study the lead researcher was senior occupational therapist at a UK Regional Hand Clinic where the research took place.

the range of experiences (Adam & Loynes 1992). To allow all aspects of their lived experience to be memorable, only participants who had undergone an operation during the year prior to data collection, (during July 2005) were included. Seven patients responded to the research invitation and a mutually convenient appointment was arranged for the interview. Table 2 gives an overview of study participants. All gave written informed consent to participate in the study and to have interviews tape-recorded and transcribed for dissemination.

### Data collection

Semi structured interviews were used to generate data with an aide memoir of open questions used as a broad guide to the conversation (Holloway & Wheeler 1996). Each interview was unique as it focussed specifically on the individuals experience (Rubin & Rubin 2005). Field notes were completed immediately after interview (Gadamer 1976), to allow reflection on issues such as context, setting and potential bias. This helped to articulate the researcher's thoughts and responses to the patients' narratives which were useful in guiding data analysis and interpretation (Kvale 1996).

### Conduct of the interviews

Participants were given the opportunity to be interviewed at either the hospital site ( $n = 5$ ) or in their own home ( $n = 2$ ). An informal 'warm up' period of friendly social conversation took place before interview, enabling development of a natural atmosphere. All interviews commenced with the same

**Table 2** Summary of respondents characteristics

Identification	Gender	Age decade	Period of disease	Disease status	Dominant hand	Hand affected
Andy	Male	80s	6 years	Waiting for left little finger proximal interphalangeal joint local anaesthetic	Right	Both
Bert	Male	60s	5½ years	Right palm and ring finger operation 11 months ago	Right	Both
Chad	Male	70s	Approx 20 years	Had left operation 15 years ago, right ring finger proximal interphalangeal joint 10 months ago	Right	Both
Doris	Female	70s	Approx 33 years	Had 3 × R op, now waiting for left little finger and ring finger proximal interphalangeal joint	Right	Both
Ed	Male	50s	3 years	R op 2 years ago, left little finger proximal interphalangeal joint 11 months ago	Right	Both
Fred	Male	70s	5–6 years	Waiting for left little finger proximal interphalangeal joint and metacarpophalangeal joint	Right	Both
Guy	Male	70s	3 years	Had left little finger percutaneous fasciotomy 9 months ago, now waiting for surgery	Right	Both

broad question: 'Please tell me in your own words what it is like to have Dupuytren's disease in your hands'. This enabled participants to answer in the way they wished, using language and style natural to them. This minimised effects from the researcher's preconceptions, biases and beliefs (Douglas 1985) and allowed rich data to be gathered (Beck 1992, Iaquina & Larrabee 2004).

Follow-on questions were single and open-ended encouraging description of their lived experience at a slow pace (Taylor 2005). Cues to guide the interviews were picked up and significant words repeated to lead to further explanations (Pallikkathayil & Morgan 1991). When descriptions of the lived experience were not clear the researcher sought clarification using non-directive questioning and probes (Sorrell & Redmond 1995).

### Data analysis

Data analysis was carried out using Colaizzi's (1978) phenomenological method (see Table 3) and carried out in the procedural order to ensure the trustworthiness and robustness of analysis. The final step of returning each exhaustive description back to the participants was described as optional and in this study transcriptions were not returned to participants, as this would not be consistent with the Hermeneutic approach (Baker *et al.* 1992). Verbatim transcriptions from interviews are included in the findings to enrich the description and reduce contamination (Beck 1992), thus increasing trustworthiness by locating the text firmly within the context (Chambers 1998). A summary of strategies used to establish trustworthiness is shown in Table 4. To

assist trustworthiness and robustness (Jasper 1994) second researcher (GB) verified data coding by independently coding two interviews. Similar codes were identified and differences resolved by discussion.

### Results

From the seven verbatim-transcribed interviews, 290 significant statements that directly related to the experience of

**Table 3** Colaizzi's (1978) procedural steps for phenomenological data analysis

- 1 Read all of the subject's descriptions (protocols) in order to acquire a feeling of them, a making sense out of them.
- 2 Return to each protocol and extract from them phrases or sentences that directly pertain to the investigated phenomenon; known as extracting significant statements.
- 3 Try to spell out the meaning of each significant statement, known as formulated meanings.
- 4 Repeat for each protocol and organise the aggregate formulated meanings into clusters of themes.
  - a) Refer these clusters of themes back to the original protocol in order to validate them.
  - b) At this point discrepancies may be noted among and or between the various clusters; some themes may flatly contradict other ones, or may appear to be totally unrelated to other ones. Refuse the temptations of ignoring the data or themes, which do not fit.
- 5 The results of everything so far are integrated into an exhaustive description of the investigated topic.
- 6 Formulate the exhaustive description of the investigated phenomenon in as an unequivocal statement of identification of its fundamental structure as possible.
- 7 A final validating step can be achieved by returning to each subject.

**Table 4** Summary of strategies to establish trustworthiness (Guba 1981)

Credibility	Tapes verified to confirm accurate transcription Field notes made at time of interview Open-ended, semi-structured interview technique
Transferability	Thick description of data
Dependability	Clear decision trail Thorough description of research method
Confirmability	Clear decision trails Open-ended, semi-structured interview technique review of data coding by second researcher to minimise bias

living with Dupuytren's disease were extracted. The significant statements were interpreted into formulated meanings, organised into clusters and four main themes emerged: Awareness of Dupuytren's Disease; Living with Dupuytren's Disease; Deciding on Treatment and Receiving Treatment.

### Theme 1: Awareness of Dupuytren's disease

This theme describes how participants become aware of the disease, often ignoring it until it affected their ability to complete activities. Participants described how they tried to gain knowledge of the disease and its process, which was often challenging. They also described how the gradual disease process affecting their hands over a long period was often unnoticed until the disease was quite advanced. Most participants said that their hand appeared to change quite suddenly without warning, almost overnight, to a bent position. Several participants described the condition as skin thickening and some made an incorrect diagnosis of arthritis. Bert describes his experience:

It seemed to take some years before I noticed that I had a thickening in the tendon and it seemed to go on and on and nothing seemed to happen and then all of a sudden it started to get a lot bigger and at the base finger got quite enlarged and it started pulling the finger over.

This unexpected occurrence, which often came as a surprise was often the point which led them to visit their general practitioner (GP). As Doris reflected:

You get this tightening and slight dull ache and I thought I'd got arthritis which I do tend to be a little bit that way and then you notice it's getting tighter and then you notice it's going a bit crooked and you still think it's arthritis and then when it goes right over, you realise that perhaps you should go to the doctors about it. That's when I discovered it was the Dupuytren's disease.

Despite having seen their GP and sometimes after an appointment with a specialist hand surgeon, participants were concerned they did not always know what the problem

was or how to gain knowledge of the condition. Two participants only realised the name of their diagnosis when they received the researcher's letter inviting them to participate in the study. As Andy said, 'He (GP) didn't mention the name of the disease or if he did I didn't hear it'. Only Fred, who had lived with the disease for some time, was able to use previously gained knowledge to identify the problem when it recurred.

Most of the participants reported they received little information from health professionals and believed they were expected to find information they needed for themselves. As Bert explained:

He [GP] made the recommendation, 'if you want to know any more, go on the Internet' and that's what I did. In fact, in this thing I carry around with me [folder], I got stuff that I downloaded mainly from American hospitals, who seem to publish everything and one or two I suppose private surgeons who are looking for work.

The Internet was commonly used as an information source which often made the process of gaining knowledge of the disease slow, difficult and confusing, as Andy reports:

On the Internet you can look up the other 4,968 or so [sites] that was on there. I used Google to get them, but I don't know how many of these are really relevant.

Participants were often surprised at changes in their hands. Usually the disease did not seem to trouble them until it made an impact on their functional ability. As Ed reflected:

It just affects my writing and you know, you've lost your sort of, you haven't got the flexibility in the fingers so much so when you're holding things, if you don't... you can't get such a good grip on things.

For Fred, the first realisation of the problem was when he experienced functional impairment:

It has never really affected me until just very recently when I still try to play cricket and I went to catch a ball and I caught the ball right on the one finger end and it was then it became obvious that I hadn't got the dexterity I've had.

Although Dupuytren's disease has a hereditary link, this did not result in increasing participants' awareness. Two participants knew that family members had had the disease but they did not find this led to a greater knowledge or understanding.

### Theme 2: Living with Dupuytren's disease

Theme 2 articulates the impact of the disease on participants' lives, the adjustments made to accommodate the disease and concerns about its progression. Participants often expressed

concerns about unknowingly putting their hand, or themselves, in danger due to the deformity. This meant they needed to be particularly aware of their environment to minimise danger when carrying out everyday activities. When the deformity was in a progressive position, participants were anxious about harming themselves. As Bert explained:

Leading up actually to the operation I found I was catching it more to the extent of even drawing blood, you know I work in printing so I...and I... perhaps get paper cuts, that sort of thing and I caught it one day and it bled quite a lot.

Doris confirms:

You don't realise very often that something is wrapped round there and you could easily snap that off or snap it and break it but as I say, I think I've been very lucky, I've been close to it sometimes.

Participants were aware of their hands being noticed by others, particularly when actions involved others. Chad explains:

They would notice towards the end I'm asking for a tankard because I'm holding the glass like that, you know what I mean and if I have pint of beer I have to ask them to put it into a tankard... you'd notice if someone was drinking out of a tankard, you know. So that's eh, very small things.

Social contact was time when awareness of the disease could result in self-consciousness, as Chad continues, 'The hand-shaking of course. That could be a bit embarrassing'.

All participants coped with the disease in a pragmatic way, stating they had to get on with it. They worked around physical problems they encountered by adjusting functional activities or using alternative methods to complete tasks. As Doris explained:

It's something like most things; you just take it in your stride. You know you jolly well that there's nothing you can do about it, so you just jolly well get on with it.

Alternative methods, or allowing additional time enabling their way of life became habitual, as Chad recalls:

Picking up a knife was a bit difficult. So you picked it up with the other hand and put it in that hand, it's... it became a habit, it was second nature, that's a time, you don't even notice it. That's the way you're picking up a knife.

All participants expressed anxiety associated with the uncertainty of the disease progression. They were concerned that the disease would progress into other fingers, therefore affecting the whole hand. Doris comments:

I didn't envisage anything other than that one finger going, I never realised and I looked round and the odd person if they had it, it was

in their one little finger. I never envisaged it would go like this (holding out both deformed hands).

### Theme 3: Deciding on treatment

This theme identifies factors influencing participants' decisions to undergo treatment. This was often complex impeded by a lack of available information, especially from health professionals. Participants emphasised they had only sought treatment when realising the importance of their hand or how the disease affected them. Chad reported:

I never had any problem with it at all. Except when as I say, when I got in my way, then I thought, right its time I got something done about this.

At the outpatient appointment all participants had been encouraged to have surgery and alternative options were not always discussed. Bert explained:

You're told that surgery is the only answer, there is a lot of concern but em, had I known then what I know now, I wouldn't have been quite so concerned.

Many reported that if they had the opportunity for more discussion about available options and potential outcomes, their fears would have been eased and they would have been happier undergoing treatment. As Andy said:

I shall probably investigate the other methods a bit more which I didn't know about. He didn't mention any alternative treatment method. To him it was just a question of cut and sew!

Participants reported they gradually built up their knowledge base about their condition. For example, at first many did not realise there was an optimum time for surgery to be conducted. Although surgery was likely to be the best and preferred treatment option it was apparent that respondents were insufficiently informed to fully participate in decision making. There was a sense that some did not feel involved in the decision to undergo surgery. If they wanted improvement surgery was the only option offered. When deciding whether to have treatment, participants weighed up the information available, trying to make sense of it and were often concerned if treatment would be worthwhile and what disadvantages it may hold. Fred, for example, was unsure whether an operation to straighten his finger, may result in loss of movement:

I don't even appreciate whether I'd be better with an operation that would make that straight and stiff, I don't know... I mean except the specialist didn't say anything with respect to that. Can I? Would I be able to get the movement on the joints as I can now for instance, if I'd had an operation to straighten.

Despite these concerns, most participants were happy with the surgical result. However, they did want more information earlier on so they could understand what was ahead.

#### **Theme 4: Receiving treatment**

Theme 4 articulates participants' experience of surgical treatment and post surgical rehabilitation. Many expressed confusion about where they were on the treatment pathway. For example, the three participants awaiting treatment were not aware when or where they would receive it, causing confusion. Some were unsure if they were on the operation waiting list or how long the wait would be. As Fred said, 'I might be on the waiting list; I'm unaware of that (laughing)'.

Information that was received about forthcoming surgery, sometimes reinforced the sense of uncertainty, as Doris reported:

Having got these couple of notes [From the hospital] saying, do you still want to be on the list? It makes you wonder, well are you going to October or is it going to be later? But anyway it's on the list, so it's going to be done.

The four participants who had received treatment had done so without adequately understanding the need for treatment and what was expected of them. Some were still confused about the treatment they had received. Thus, although Bert conscientiously carried out the postoperative care, he did not understand why it was necessary:

Mr (Consultant) made the point that you must wear this splint and I did, but I thought at the time and I still do that its counter productive because they favoured obviously trying to get the hand straight and yet the whole natural thing with the hand is to want to make... you know, to close it.

Some also spoke about the discomfort of wearing the splint. Bert recalls:

Then I was fitted with the, the night splint and it was agony to put it on. When I put it on, I was getting pains right up (pointing to the arm) and was taking painkillers going to bed.

The pain did subside over time but for some the experience raised doubt over future treatment being sought. Pain was experienced postoperatively by several which had consequences later on when considering treatment for other fingers leading to a negative view of treatment, as Doris explained, 'So it does tend to put you off the next time'.

Following treatment, some participants continued to use the advised techniques for improving mobility. As Guy said:

If I'm sitting down watching TV, I'm doing this, pushing the fingers back like that. I put them into hot water and that does give it a little bit more flexibility.

After discharge they had not been told to continue with techniques; however, they were still followed in the hope of minimising reoccurrence requiring repeated surgery. As Burt explained:

He [Consultant] has recommended that I rub this (pointing to the scar) but I still use the E45 cream on the scar (rubbing the scar), well use it on my hands generally where I tend to rub this side of the scar as well, whether that will keep it down to prevent an operation in the future I don't know. I mean if it gets no worse, well no, there isn't a problem.

The themes have identified participants' experiences of living with Dupuytren's disease. A final step in Coliazzini's (1978) method is formulating a fundamental structure of the phenomenon studied. This is shown in Table 5.

## **Discussion**

This study has explored and described the experience of living with Dupuytren's disease. Four interlinking themes were identified which articulate the process of recognising the disease, living with the disease and adapting to the resulting progressive deformity of the hand, deciding on treatment and the experience of surgery. Integral to each theme was the lack

**Table 5** Fundamental structure of living with Dupuytren's disease

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People living with Dupuytren's disease often deny the first stages of the condition, gradually and unconsciously adapting around the problem. The realisation that they have the condition is a surprise when individuals suddenly experience difficulty in completing activities. This highlights the effect of the disease and forces them to acknowledge their situation. Once aware of the problem, they seek guidance but often remain mystified about what the problem is and how it can be improved. They seek information to improve knowledge of their problem often going to considerable effort to gather such information. The disease is seen as an inconvenience or nuisance, which they attempt to overcome through seamless adaptation to maintain their independence, which is of primary importance to them. Sufferers are pragmatic in their approach to the disease, often juggling their independence with the dangers to which they are potentially susceptible. People living with the disease are a valuable source of information for new people living with the disease, yet they face uncertainty of their own care, often only gaining information when medical intervention becomes appropriate. Many balance the decision of having treatment with unanswered concerns and the desire to maintain their functional ability. After treatment they continue with exercises habitually and feel empowered to affect future treatment being required.

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of information received from health professionals about the disease at each stage of its progression.

In Theme 1: Awareness of Dupuytren's disease, participants described how the gradual disease process affecting their hands was often unnoticed until the disease was advanced. Often the condition was ignored until it affected ability to complete activities. Usually this was the point at which medical help and advice was sought. Yet despite having seen their GP and sometimes after a specialist hand clinic appointment participants did not know what the condition was or how to gain information about it.

The Health Care Commission (2005) has reported that communication between health professionals and patients is frequently poor and that patients often lack basic information about their condition and possible care. However, people need prompt, accurate, up-to-date and accessible information to understand their health problem, its potential impact and to exercise choice in its management (DH 2002, 2005b). Nurses have a role to play in helping people recognise Dupuytren's disease understand its progress and the available treatment options.

None of the participants in this study had been given any written information about their condition by health professionals, which is regarded as an essential aspect of care (DH 2004, 2005b). Miers (1999) suggests patients seek information elsewhere when the health care system fails to understand and meet their needs. Many reported they were advised by health professionals to find out more about their disease themselves by searching the internet, or they chose to do this themselves. Many people do not have internet access and there is no guarantee that such material is consistent and reliable. Although some people are able to make effective judgements about the quality of web-based information (Rogers & Mead 2004, Kivits 2006) there is evidence that patients reject NHS sites which contain reliable information in favour of more accessible user-friendly sites including patients' experiences and contributions (Sillence *et al.* 2007). Patients need up-to-date and accurate information to understand their condition and play an active role in the partnership with health professionals about their treatment (Northway 2000).

Coulter (2005) suggests that one thing patients want most from primary care is fast access to reliable health advice. This study found that people with Dupuytren's disease do not receive the information and support they need. In Theme 2: Living with Dupuytren's disease, the ways in which people coped with the disease and adapted their activities to maintain independence are described. All participants expressed anxiety associated with the uncertainty of disease progression and concern that the disease would spread into

their other fingers. None had a clear picture of the disease or the treatment options available.

Hands are fundamental to much human activity because of their role in manipulation of objects. Many participants experienced problems with functional aspects of their daily life due to difficulties with dexterous tasks requiring fine manipulation. This suggests that aspects of living with hand deformity experienced by those with hand injuries and rheumatoid disease (Whalley *et al.* 1997, Gustafsson *et al.* 2000) were also encountered by people with Dupuytren's disease. Although the appearance of their hand was not something that people living with Dupuytren's disease were greatly concerned about, they experienced embarrassment in social situations. They were also worried that they could harm themselves and, like those with other hand deformities (Gustafsson *et al.* 2000, Yoshida & Stephens 2004), had to allow more time to undertake activities or use alternative methods to overcome limitations.

### Relevance to clinical practice

For any person with a long-term condition, deciding on the best treatment option is a complex decision which involves consideration of a range of factors including the likely progression of disease and personal factors such as age and health status. The lack of information given to patients with Dupuytren's disease impeded their ability to be informed partners in decisions about their treatment and care. Most described health professionals as adopting a paternalistic approach, which presented surgery as the only option available. Many participants had concerns about the prospect of surgery to their hand and the potential outcomes. Information is one of the most effective ways to reduce preoperative anxiety, which can be detrimental to recovery (Carr & Thomas 1997, Mitchell 1997). Participants in this study reported that having more information and the opportunity to discuss available treatment options and potential outcomes would have reduced their fears and they would have felt more confident about undergoing surgical treatment.

### Limitations

A possible limitation to this study was not returning the interview interpretations to respondents (Colaizzi 1978, Sandelowski 1986). However, to do so would have compromised the credibility of the Hermeneutic approach as discussed in the method section (Baker *et al.* 1992). Alternative strategies were used to enhance the credibility of this study by using field notes, type of interview technique and



verification of interview transcription, as highlighted in Table 4 (Guba 1981).

## Conclusion

This study has explored the lived experience of Dupuytren's disease using a phenomenological approach in one Regional Plastic Surgery Unit. The findings from this study demonstrate that people living with Dupuytren's disease need more information regarding their condition and its treatment to be better informed about their condition and play an active part in treatment decisions. The main recommendation is to provide people with Dupuytren's disease with more information about the condition, its progression and treatment options available. Nurses and health professionals who are directly involved in the care of these patients are in a key position to provide this information. Written information is particularly needed to ensure patients are correctly informed and it may also be useful to recommend literature and websites that provide accessible, accurate and up-to-date information to further meet their informational needs.

Nurses in a large range of clinical settings will encounter people with Dupuytren's disease and are often the first point of contact. Greater awareness of the condition is needed by nurses, GPs and other community health professionals about the disease. It is important they receive education about the disease so they can play a part in its recognition and contribute to a streamlined and multi-professional service that meets patients' needs from onset until treatment completion.

## Acknowledgements

The authors are grateful to all the individuals who participated in this study.

## Contributions

Study design: ALP, GB; data collection and analysis: ALP, GB and manuscript preparation: ALP, GB.

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